News focus

Green light for selected baby

The British Human Fertilization and Embryology Authority has for the first time allowed pre-implantation diagnostics to be used for the benefit not only of the unborn child but also of a seriously ill sibling whose life it may save. **Michael Gross** reports.

Zain Hashmi is a three-year-old little boy from northern England with big brown eyes and a fatal disease, beta thalassaemia major. As his bone marrow is unable to produce sufficient numbers of red blood cells, he needs regular transfusions and is unlikely to survive for long unless transplanted with suitable stem cells. These could come from the bone marrow of a donor with matching tissue type, but neither in his family of seven nor in the national donors databases could a match be found. They could also come from the umbilical cord of a sibling yet to be conceived, if the baby has the matching tissue type.

As Zain's parents have got five children already and feel that time is running out for trying the natural way, they applied for permission to use *in vitro* fertilization (IVF) combined with pre-implantation genetic diagnosis (PGD) to make sure that their sixth child will not only be free of the disease, but also have the stem cells that can save Zain's life.

In Britain, sensitive bioethical issues like this one are decided by the Human Fertilization and Embryology Authority (www.hfea.gov.uk) chaired by Ruth Deech of Oxford University. Britain is one of the leading countries in developing controls on new embryo research. The HFEA is responsible for licensing any research and any breaches constitute a criminal offence. In the US, for example, controls on federal funding for embryo research are in place, but private companies funding their own work are entirely without regulation. Decisions by the HFEA therefore carry more weight than might otherwise be the case. And on December 13th last year, the HFEA ruled that in principle PGD may be used to create a life-saving sibling for a seriously ill child, but that a licence committee would have to approve every case individually on its merits, following a set of very stringent conditions. Ruth Deech said: "Where PGD is already being undertaken, we can see how the use of tissue typing to save the life of a sibling could be justified. We would see this happening only in very rare circumstances and under strict controls." These include that all other possibilities have been exhausted, and that the parents receive counselling on the ethical implications. The authority strictly ruled out similar procedures if the tissue were to benefit one of the parents.

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Apart from the knee-jerk reaction of the anti-abortionist group "Life" who felt that being born into a loving family as a life-saviour for one's brother "could be a terrible burden for any person to shoulder", and the misleading "designer baby" headlines, there was little doubt that this general decision was well-considered. Still, the authority took another nine weeks to decide on the individual case of Zain Hashmi, possibly in an attempt to let any fundamentalist fury exhaust itself before coming to the crunch point of a case that some might consider a dangerous precedent for other, less defendable ones.

On February 22 the HFEA gave the go-ahead for the Hashmi family. They will now be free to have their IVF / PGD treatment at the Care fertility clinic in Nottingham, although the samples will be sent to the US for the diagnostic part of the procedure. Coincidentally, a baby girl whose parents underwent the same procedure for the benefit of a sibling with leukaemia, but travelled to the US to avoid having to wait for the HFEA's decision, was born in a British hospital a week earlier.

Reactions in the British press were generally positive, with the predictable opposition from Life's spokesman Peter Garrett and some concerns raised by church bodies. Meanwhile, half a dozen other British couples with similar problems are said to be queuing to have their cases considered. Apart from the Nottingham clinic, a London hospital is also planning to offer this treatment.

However, Deech emphasised the planned controls on the procedure. A child born after the genetic diagnosis would have the same protection as any other child being considered for further transplants, such as bone marrow donation, she said. "The wishes of the parent alone would be insufficient in deciding whether or not such a donation could be made," a spokesperson said.

Dr Simon Fishel at the Nottingham hospital said: "It is always difficult to reassure people against bad practice and abuse. Certainly in this country the regulations will assure that this will not take place. I think it is a beneficial procedure and it will be used carefully and guardedly."

Michael Gross is a science writer in residence at the school of crystallography, Birkbeck College, University of London. He can be contacted through his web page at www.michaelgross.co.uk.